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1115 Waiver Comments

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Thank you for the opportunity for The Arc to present recommendations on the goals and strategies of the Illinois Medicaid 1115 Waiver. The Arc represents individuals with intellectual and other developmental disabilities (I/DD) and their families.

At this time, neither the concept paper nor other materials shared with The Arc clearly state how this Medicaid Transformation 1115 Waiver will change the way services will be provided, especially to persons with I/DD, and how it will impact our community services capacity and quality.

The template for rebalancing the Developmental Disability System in Illinois is: [“Illinois at the Tipping Point - Blueprint for System Redesign in Illinois Update”](#), a seven year outline on necessary changes to establish a person-centered community based system.

Some concerns that we at The Arc have are:

1. This is the next step toward Phase III of Integrated Care? From the concept paper, “The waiver will provide the flexibility needed to deliver appropriate and essential HCBS waiver services, also referred to as “long-term supports and services” (LTSS), in a coordinate fashion through managed care entities and their provider networks.”
2. Do we have the money within the system to do this huge transformation? The funding of community services continues to be among the lowest in the nation.

3. The possible elimination of important specialized services for individuals with intellectual and other developmental disabilities.
4. The need for free standing, non-conflictual service coordination in all community and institutional settings.

We need to further understand:

1. Needs Assessment for the 1115 Waiver
2. Eligibility for 1115 Waiver Services
3. Cost Analysis of the 1115 Waiver & Disability Services
4. Service Definitions or Redefinitions in the 1115 Waiver
5. Provider Tax
6. Will the Waiting List End?
7. Employment First & Flexible Day Services

Based upon the concept paper, we offer the following recommendations for the 1115 Waiver and emphasize the need for flexible supports/services offered in inclusive community settings.

## **HOME AND COMMUNITY BASED INFRASTRUCTURE, COORDINATION AND CHOICE**

1. Maintain the social model of disability, rather than shifting back into a medical model. Viewing disability as a medical condition, for people who rely on Medicaid funded services to achieve a wide variety of personal goals, is extremely limiting.
2. Continue and expand the Governor's Rebalancing Initiative in the new 1115 Waiver. Reward the transition of individuals from institutional settings through development of capitation model that incentivizes payment for Home & Community Services over institutional services. Pay for performance indicators that are tied to successful transition to community services.
3. End the PUNS Waiting List within seven years or sooner.
4. 1115 Waiver services/supports to individuals with I/DD must be flexible and offered in inclusive settings and emphasize employment first.
5. Innovate the menu of community living options to include but not be limited to: CILA, Intermittent CILA, supported living, Home of Your Own, cooperative living arrangements, live-in caregivers, etc...
6. Rates for community services in Illinois remain low, with the majority of people served in eight-person residential settings and attending large, congregate day programs. Illinois rates for developmental disability community services should

be increased to the national average of \$44,396 from the current \$31,002. Pay for performance incentives that are tied to creating smaller, more integrated community living settings and flexible day service options emphasizing employment and community integration.

7. Wages for direct care staff will increase by \$3.00 per hour in the first year of the 1115 Waiver.
8. Maintain and expand the current free standing 18 non-conflictual Independent Service Coordination systems for person-centered planning and advocacy for people with I/DD and their families in all community and institutional settings.
9. Expand and enhance services such as crisis stabilization provided in community settings, in-home supports and services, flexible day services, retirement services for aging adults and employment related services. Development of community based services for people with dual diagnosis and/or involvement in the criminal justice system will support efforts to make community living a reality for all.
10. There needs to be a statewide program for individuals with I/DD to develop leadership skills, address public policy and advocate for a system that meets their individual needs. Currently this is the Alliance.
11. In addition, there needs to be a statewide Partners in Policy Making Program for families and individuals with I/DD: <http://mn.gov/mnddc/pipm/>
12. The new 1115 Waiver should offer self-directed, personal care or other services to meet the needs of those not on the current I/DD Waiver.
13. The 1115 Waiver should have a strong independent ombudsman to oversee a rigorous appeal process with the necessary infrastructure to advocate for the rights of persons with I/DD in the system.
14. Create a new service eligibility category: “Medically Needy” Children. This category would waive parental income because these families experience extraordinary expenses for ongoing medical needs.
15. The new 1115 Waiver must implement aggressive and culturally competent education and outreach strategies to ensure individuals with I/DD have accessible information. An expected outcome of this waiver should be a Cultural Competence Plan.
16. Supported Housing is not a model for individuals with I/DD.

## DELIVERY SYSTEM TRANSFORMATION

1. The UIC-Division of Specialized Care for Children's Habilitation Clinic should be reopened. This clinic was a state-of-the-art integrated developmental pediatrics multi-specialty clinic for children with I/DD and medical needs. The Clinic was also a key training site for future generations of primary care providers.

## 21<sup>st</sup> CENTURY HEALTH CARE WORKFORCE

1. College of Direct Support, University of Illinois at Chicago, Dept of Disability and Human Development, developed a partnership with the College of Direct Support through a grant from the Illinois Council on Developmental Disabilities. This nationally recognized resource should be utilized here in Illinois for direct care staff who support individuals with I/DD:  
<http://directcourseonline.com/directsupport/>
2. Loan repayment and other strategies should also include Qualified Intellectual Disability Professionals (QIDP) who have Bachelor's Degrees or Master's Degrees. The QIDP's are responsible for developing and implementing person-centered plans with persons who have I/DD.
3. We should work with the community colleges in Illinois to establish certificate and Associate Degree training programs for persons currently employed as Direct Support Professionals, as well as those interested in entering the field. Allow them to receive practicum credit while working in the field.
4. Reinstate the regionally based training for respite workers (originally established by old Department of Developmental Disabilities), which included CPR and First Aid training, along with a "DD 101", and expand it to include PAs and Personal Support Workers who are hired by consumers in the self-directed (waiver) mode.

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